

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**



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| DEPARTMENT ON DISABILITY SERVICES   | Policy Number: 8.2       |
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| Cross References and Related Policies:<br>Psychotropic Medications; Positive Behavior Support; Restrictive Procedures; Affirmation,<br>Promotion and Protection of Individual Rights and Freedoms; Human Rights Review; Office of<br>Rights and Advocacy. |                          |
| Subject: Human Rights Definitions   |                          |

1. PURPOSE

This purpose of this policy is to provide consistent definitions of all terms related to the affirmation, protection and promotion of the rights of individuals with disabilities who receive services funded or arranged by the District of Columbia Department on Disability Services and its providers.

2. APPLICABILITY

This policy applies to all DDS employees, subcontractors, providers, vendors, consultants, volunteers, and governmental agencies that provide services and supports to individuals with disabilities.

3. AUTHORITY

The authority for this policy is established in the Department on Disability Services as set forth in D.C. Law 16-264, the "Department on Disability Services Establishment Act of 2006," effective March 14, 2007 (D.C. Official Code § 7-761.01 *et seq.*); and D.C. Law 2-137, the "Mentally Retarded Citizens constitutional Rights and Dignity Act of 1978," effective March 3, 1979 (D.C. Official Code § 7-1301.01 *et seq.*).

4. DEFINITIONS

The Abnormal Involuntary Movement – or AIMS – Scale. The AIMS (Abnormal Involuntary Movement Scale) aids in the early detection of tardive dyskinesia. This

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

simple checklist takes only 10 minutes to complete and uses a five-point rating scale for recording scores for seven body areas: face, lips, jaw, tongue, upper extremities, lower extremities, and trunk. It is used to monitor movement disorders for individuals taking any kind of antipsychotic medication.

Aversive. The use of unpleasant, painful, uncomfortable or distasteful stimuli to try to change an individual's behavior. The use of aversive interventions is strictly prohibited in all programs funded or operated by DDS.

Axis I Mental Disorder. According to the Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR, published in 2000 by the American Psychiatric Association, a mental disorder is a "clinically significant behavioral or psychological syndrome or pattern that occurs in an individual...is associated with present distress...or disability...or with a significant increased risk of suffering " but that "...no definition adequately specifies precise boundaries for the concept of "mental disorder...different situations call for different definitions." Axis I Mental Disorders are classified in the DSM-IV-TR to refer to all mental disorders except Personality Disorders and Mental Retardation. Examples of Axis I disorders include, but are not limited to, schizophrenia, major depression, and other major affective disorders.

Behavior Support Committee. A Behavior Support Committee reviews and approves or rejects all behavior plans that incorporate restrictive methods, including restraint and time-out, and reviews ongoing behavior plans that incorporate restrictive methods, including restraint and time-out. The Committee shall include persons knowledgeable in behavior support procedures, including administrators and staff employed by the provider who are responsible for implementing Behavior Support Plans, but not those directly involved with the plan being reviewed. The authors of the Behavior Support Plan may attend Committee meetings to provide information and to facilitate incorporation of suggested changes. One Behavior Support Committee may serve more than one community service provider.

Behavior Support Plan (BSP). A component of the Individual Support Plan (ISP) that defines individually tailored behavior supports designed by a licensed professional or behavior management specialist supervised by a licensed professional to assist an individual in ameliorating and/or eliminating the negative impact one or more challenging behaviors have on his or her daily life. The BSP identifies strategies and services necessary to support and encourage the person in his or her decision to reside within the community; decrease the impact of a behavioral event; to assist the person in developing alternative and more effective communication, adaptive and coping mechanisms; and enable the person to achieve positive personal outcomes. The Behavior Support Plan is based on an understanding that there are reasons for challenging behaviors and those in a person's life must work to understand the underlying reasons. Therefore, BSPs must be based on a thorough and thoughtful functional assessment that results in a BSP with steps and methods to help the individual address his/her challenging behaviors.

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

Capacity. The mental ability to understand the nature and implication of a decision (that there is a choice to be made) and the information (the alternatives) being presented; as well as, the ability to communicate that decision or give informed consent.

Challenging Behaviors. Behaviors that are seriously and consistently disruptive to the physical or social environment, that pose a significant danger to oneself or others, or that interfere with the attainment of learning goals or personal outcomes identified through an ISP process. Such behaviors may result from internal factors, from past learning or from environmental factors.

Chemical Restraint. The application of emergency psychotropic medication to control acute, episodic behavior that restricts movement or function of the individual for the protection of the individual or others from harm. The use of chemical restraint is strictly prohibited.

Complaint. A complaint is the formal expression by any individual of their dissatisfaction or unhappiness with supports and services or treatment provided by or through DDS, their provider agency, or someone employed or volunteering to provide them with supports and services.

Emergency Use of Restrictive Controls. Restrictive controls that are used in an emergency situation to briefly control behaviors that pose a risk of harm to the individual or others, or to prevent the serious destruction of property, in a situation when those behaviors were not anticipated and where there is no approved Behavior Support Plan that incorporates the planned use of restraint or other restrictive techniques.

Evidence Based Practice. Evidence-based practice is the conscientious, judicious use of current best evidence in making decisions about care to individuals with disabilities. This approach is derived from the concept of evidence-based medicine, which began to emerge in 1980 as physicians first performed systematic reviews of the evidence for preventive services as a step in writing clinical practice guidelines. There are six steps in the provision of evidence-based practice: (1) decide what information is needed; (2) formulate one's information needs in the form of a question that a research study could answer; (3) search the published literature to find the evidence; (4) decide which studies are valid and applicable to the individual at hand; (5) apply the findings to the individual; and (6) evaluate the outcomes.

Fact-finding. An inquiry undertaken to ascertain the relevant circumstances surrounding a complaint and to provide the basis for a written report that contains appropriate recommendations on the matter being examined and reasons for the recommendations. Fact-finding procedures may include: 1) obtaining documentary evidence, 2) personal interviews, 3) group meetings, or any combination of the above. People who perform this function shall have:

- Experience as a grievance examiner, arbitrator, administrative judge, or investigator; or

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

- Satisfactory completion of a course for grievance examiners, arbitrators, or investigators, and,
- Good working knowledge of the principles, systems, methods and administrative processes for providing services to individuals served by DDS and/or community service providers..

Functional Assessment. A method, such as systematic observations and questionnaires, designed to determine the behavioral consequences that maintain challenging behavior. Functional assessments are used to help build respectful support plans for persons with challenging behaviors and are developed with input from those who know the individual best.

Grievance. A grievance is the formal expression by any individual of their dissatisfaction or unhappiness with supports and services or treatment provided by or through DDS, their provider agency, or someone employed or volunteering to provide them with supports and services. A grievance differs from a complaint only in procedures used to resolve the individual's dissatisfaction or unhappiness and the severity of the underlying issue. Typically, a grievance deals with lesser violations or restrictions of basic human rights or freedoms that would not in the usual course be subject to the reporting requirements of the Incident Management Policy or eligible for administrative proceedings under Medicaid, *e.g.*, request for services denied.

Grievance File. A separate file that contains all documents related to the grievance filing and grievance hearing.

Grievance Hearing. An administrative hearing conducted by a Grievance Examiner that provides the individual filing a grievance an opportunity to present supporting evidence, including witnesses; and the party against whom a grievance has been filed the opportunity to respond to the grievance and provide supporting evidence, including witnesses. A verbatim transcript of the hearing shall be made. The person that serves as the Grievance Examiner shall issue a written decision based upon all evidence and arguments presented during the hearing. People who perform this function shall have:

- Experience as a grievance examiner, arbitrator, administrative judge, or attorney. Attorney, and,
- Good working knowledge of the principles, systems, methods and administrative processes for providing services to individuals served by DDS and/or community service providers.

Human Rights and Freedoms. Basic rights and freedoms to which all humans are entitled, including but not limited to life, liberty, freedom of thought and expression, privacy, religion, freedom of choice, self-determination and equality before the law.

Human Rights Advisory Committee (HRAC). The Department on Disability Services HRAC is charged with the responsibility of providing guidance and oversight in all matters pertaining to the human rights of individuals receiving services as part of the DDS service delivery system. Through its oversight and recommendations, the

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

Committee safeguards and promotes the rights and freedoms of all consumers of Department on Disability Services by ensuring that all allegations of human rights violations are properly reviewed and resolved. The Director of DDS appoints members and the Chairperson of the HRAC. The Committee is comprised of community representatives, community service providers, consumers, family of consumers, advocates, and DDS staff.

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Informed Consent. The knowing consent voluntarily given by an individual (or by the individual's guardian, if applicable) who can understand and weigh the risks and benefits involved in the particular decision or matter. Whenever the informed consent of the individual or guardian is required, the following criteria shall apply:

1. The consent of the individual or guardian shall be in writing and filed in the individual's record;
2. The written consent shall be dated and shall expire upon completion of the specific procedure for which it applies; in any event an informed consent shall expire one year after it is signed;
3. No coercion or overbearing inducement shall be utilized to obtain consent;
4. A written record shall be made which:
  - a. details the procedure utilized to obtain the consent;
  - b. identifies the name, position, and affiliation of the individual securing the consent; and
  - c. summarizes the information provided to the individual from whom consent is secured.
5. The person securing the consent shall:
  - a. explain the intended outcome and nature of, and the procedures involved in, the proposed treatment or activity;
  - b. explain the risks, including side effects, of the proposed treatment or activity, as well as the risks of not proceeding;
  - c. explain the alternatives to the proposed treatment or activity, particularly alternatives offering less risk or other adverse effects;
  - d. explain that consent may be withheld or withdrawn at any time, with no punitive action taken against the individual;
  - e. present the foregoing information in a manner which can be understood by the individual, or guardian if any; and
  - f. offer to answer questions that the individual or guardian may have regarding the matter for which consent is being sought.
6. The appropriateness of the consent shall be reviewed as part of the annual review of the individual's ISP.

Mediation. A form of dispute resolution in which a third party, a trained professional mediator, facilitates the resolution process by assisting the parties in reaching a voluntary solution to a complaint filed by an individual. The mediator does *not* impose a resolution on the parties or make any decisions about fault.

Mediation Settlement Agreement. A binding settlement agreement completed if parties reach resolution of a mediated complaint. A Mediation Settlement Agreement is signed

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

by each party participating in the mediation and reflects the resolution decided by the parties.

Mediator. A person who has completed a mediation training of at least forty (40) hours and has experience mediating at least twenty mediations as a co-mediator or sole mediator.

Most Integrated Setting. Settings, modes of services and styles of living or working that are as integrated as possible, in settings that are typical and age-appropriate in the community, that interfere the least with the individual's independence, and that promote the opportunity to actively engage with other people who live or work in that community.

Office of Rights and Advocacy (ORA): The Office of Rights and Advocacy, in the Office of the DDS Director, maintains overall responsibility for the coordination of all of DDS's advocacy activities and rights promotion and protection activities.

Other Responsible Parties. As used in these policies and procedures, this phrase is meant to encompass the guardian, attorney and advocate of an individual receiving DDS-funded or arranged service as well as other individuals and entities that have a legal responsibility to monitor providers.

Permanent Limited Guardian for Healthcare Decisions. An individual who is appointed by a court order to make medical decisions based on substituted judgment as a guardian for someone else pursuant to D.C. Official Code § 21-2047. The individual named as the permanent limited guardian may include but is not limited to the person's parents, siblings, next of kin, court-appointed advocate, court-appointed Probate attorney, or others.

Positive Behavior Support (PBS). Positive behavior support is an approach to addressing challenging behavior that focuses on changing the physical and interpersonal environment and a person's skill deficits so that the individual is able to get his/her needs met without having to resort to challenging behavior. Positive behavior supports are approaches and techniques based on insight into that which is motivating an individual's difficult behavior, which focus on reducing the likelihood that problem behaviors will occur by changing situations and events that trigger behaviors. PBS approaches also work to improve the overall quality of individual's lives. Positive behavior support is based on respect, dignity, and personal choice. It helps develop effective ways of meeting an individual's needs to reduce challenging behaviors. Different individuals will require different positive supports. Common types of support are:

- Assisting a person to live in a home which is safe, attractive, and in a location that is readily accessible to the community, activities, friends, and relatives; and
- Providing a person with opportunities and assistance to:
  - Learn how to make choices and exercise personal power;
  - Manage daily activities, pursue personal goals, and access good health care;
  - Form and maintain significant friendships and relationships; and

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

- Participate in a broad range of activities that the person enjoys and which promote positive recognition by self and others. This includes work, leisure, socialization and personal interests.

PRN. “As needed” (*pro re nata*). PRN refers to a standing order for a medication or procedure, specifying the circumstances for which they would be used. The prescription and/or administration of psychotropic medication to an individual receiving DDA services to a PRN basis is strictly prohibited.

Provider. A private or public entity contracted with the District of Columbia Government who provides services and/or supports to individuals receiving services as part of the Department on Disability Services service delivery system.

Provider Human Rights Committee. A Committee established by a provider agency to review allegations of rights violations, serious reportable incident investigations, behavioral plans, etc., for receiving services to ensure that the human rights of individuals in their care are protected.

Psychotropic Medications. Medication prescribed specifically to stabilize or improve mood, mental status, or behavior. Common psychotropic medication include neuroleptics or anti-psychotic (including major tranquilizers); anxiolytics (including minor tranquilizers, sedatives and hypnotics); stimulants, mood stabilizers; and anti-depressants. Anticonvulsants and other classes of drugs are included in this category when they are prescribed for behavioral purposes.

Representative. A person chosen by the individual in order to assist them in communicating their issues and representing their interests. This could be a self-advocate, family member, friend, significant other, guardian or attorney.

Restraints. Actions that limit a person’s voluntary movement for the purpose of keeping that person from doing serious harm to him/herself or others. Restraints are permitted only in extraordinary circumstances, where personal safety is at risk and positive behavior supports have not yet succeeded. The three types of restraints are physical, chemical and mechanical. Approval for any restraint must follow the review and approval guidelines set forth in the psychotropic medications, human rights and restrictive control restrictive control review policies and procedures. All restraints are restrictive procedures. Restraints can be physical, mechanical, and chemical.

1. *Chemical restraint* means a prescribed medication for the purpose of modifying, diminishing, controlling, or altering a specific behavior. *PRN use of psychotropic medication is considered chemical restraint and is prohibited.* Chemical restraint does not include the following:
  - a. Medication prescribed for the treatment of a diagnosed disorder as found in the current version of the American psychiatric association's "Diagnostic and Statistical Manual" (DSM); or
  - b. Medication prescribed for treatment of a seizure disorder.

**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

2. *Emerging methods and technology* means new methods of restraint or seclusion that create possible health and safety risks for the individual, including methods or technology that were not developed prior to the effective date of this policy;
3. *Mechanical restraint* means a device that restricts an individual's movement or function applied for purposes of behavior support, including a device used in any vehicle, except a seat belt of a type found in an ordinary passenger vehicle or an age-appropriate child safety seat; and
4. *Physical restraint* means a hands-on method that is used to control an identified behavior by restricting the movement or function of the individual's head, neck, torso, one or more limbs or entire body.

Restrictive Control. Any device and/or procedure that:

1. Restricts limits or directs a person's freedom of movement (e.g., mechanical restraint, manual restraint, one-to-one staffing, or time out procedures);
2. Restricts access to personal property or removes something the person owns or has earned;
3. Is prescribed medication to stabilize, alter and/or change behavior or mood; and/or
4. May compromise the human or civil rights of an individual.

Restrictive Control Review Committee (RCRC). A subcommittee to the HRAC, which advises the DDS Deputy Director for the Developmental Disabilities Administration and DDS Director via the HRAC of the status of allegations of unauthorized use of restrictive controls, reviews all uses of restrictive controls for DDS individuals as well as the procedures developed for use of restrictive controls, and ensures that people providing services adhere to the DDS Behavior Support and Restrictive Controls policy.

Self Advocate. A person with developmental disability that advocates on their own behalf and/or on the behalf of others with developmental disabilities.

Serious Reportable Incident. An incident which, due to its significance or severity, requires immediate notification to, and investigation by, Incident Management Enforcement Unit and external authorities (such as the Inspector General, the Department of Health's Health Care Regulation and Licensing Administration), in addition to internal review and investigation by the provider agency.

Side Effects. Secondary effects of a drug, which are usually undesirable and different from the therapeutic effect.

Substitute Healthcare Decision-Maker. Any individual authorized (by statute or by common law) to make decisions on behalf of another person to give or refuse consent to medical treatment options recommended by the person's physician. The decision whether or not to give consent shall be based on the known wishes of the person, but if the wishes of the person are unknown and cannot be determined, then the decision should be based on a good faith belief as to the best interests of the person.

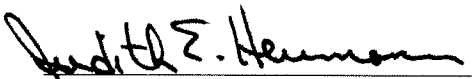


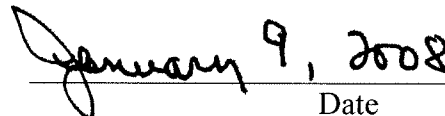
**GOVERNMENT OF THE DISTRICT OF COLUMBIA**  
**Department on Disability Services**

Substituted Judgment. Making a decision that conforms as closely as possible with the decisions that the individual would have made, based upon knowledge of the beliefs, values, and preferences of the individual, as defined in D.C. Official Code § 21-2011(25A).

Tardive Dyskinesia (TD). One of the muscular side effects of anti-psychotic drugs, especially the older generation like haloperidol. TD does not occur until after many months or years of taking antipsychotic drugs, unlike akathisia (restlessness), dystonia (sudden and painful muscle stiffness) and Parkinsonism (tremors and slowing down of all body muscles), which can occur within hours to days of taking an antipsychotic drug. TD is primarily characterized by random movements in the tongue, lips or jaw as well as facial grimacing, movements of arms, legs, fingers and toes, or even swaying movements of the trunk or hips. TD can be quite embarrassing to the affected patient when in public. The movements disappear during sleep. They can be mild, moderate or severe.

Temporary Emergency Guardian for Healthcare Decisions. An individual who is appointed by court order to make medical decisions based on substituted judgment as a guardian for someone else, whose authority is for a specified period of time, and who usually is appointed in an emergency care or urgent care situation pursuant to D.C. Official Code § 21-2046.

  
Judith E. Heumann, Director

  
Date